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Presidential Address

On the State of Our Society

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I am proud and honored today to speak with you as the thirty-second president of the American Society of Human Genetics. In searching around for a theme suitable for inaugurating our Society's activities in a new decade, I did what presidents in this situation always do, namely, look back at past presidential addresses to our organization. That historical exercise was both revealing and unsettling, for I found that no fewer than 17 of my 31 predecessors had not given such addresses at all, and that those who had spoken had chosen a range of scientific, clinical, educational, and social topics so broad as to offer no particular guidelines or constraints. This set me to thinking about the presidency of our Society in particular, and about our Society in general.

It occurs to me that the presidents of the American Society of Human Genetics are animals with a peculiar life cycle. Having achieved a reasonably successful academic career by being diligent, well organized, and rooted, they are suddenly designated to lead an organization devoted to being casual, unorganized, and itinerant. Having lived with the notion that scientific journals are organs which exist solely to disseminate worthwhile science, they discover that our Society's journal is its economic lifeline and, in some unofficial but real way, its publisher is our membership office. Some time is required for these realities to sink in, but that is no problem. Our designated executives spend an entire year as presidents-elect during which time they have absolutely no responsibility, and are not bothered by past or present leaders. Rather they are allowed, like Ferdinand the Bull, to romp in the field and sniff the flowers. Then, however, January first arrives and our presidents begin their year of leadership and service. The early months are consumed with requests for help about such momentous matters as to why a member's journal was not received on time, or, in more critical cases, not received at all. Very rarely are there requests for letters to congressmen or federal agencies regarding health legislation because the Society per se has been miraculously successful in remaining

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invisible to the outside world. Whatever the other chores, they are trivial compared to the president's single major task—to preside over the Society's annual meeting in the fall. This tour de force involves working on the selection of the scientific program, conducting business at the marathon meeting of the Board of Directors, and the temporally more modest meeting of the general membership, orchestrating the plenary scientific session and the banquet, and, if so desired, delivering the presidential address. Then, reminiscent of a salmon successful at spawning, the exhausted president recedes from view.

Intrigued, then, as I was by these musings about our Society, I decided to talk with you today about its present state: who we are; what we do and don't do; and how we look to ourselves and to the outside world.

To those of you who may be wondering why, when provided with so large a captive audience for so short a time, I choose to spend some precious moments on the seemingly mundane vital statistics of our organization, a few words of explanation. Our Society, like the growth media with which many of us propagate cells, is remarkably heterogeneous—a sprinkling of dentists, nurses, lawyers, and undergraduates added to a basic mixture of PhD's, MD's, and MS's. During the past few years, I have become increasingly curious about the quantitative aspects of this "gemisch" because I've been warned, on some occasions, that our Society was being taken over by the genetics associates, and, on others, that our clinical geneticists were so disenfranchised as to warrant the creation of a new organization. It seemed pertinent, therefore, to find out a bit more about who we are and what we do. Neither piece of information has been as easy to come by as one might, a priori, expect.

Believe it or not, no one at the University of Chicago Press or in the offices of our overworked and underappreciated secretaries could tell me precisely how many of us there are in the Society, much less how we got this way. But surely, said I, there must be a running record of our membership which contains at least their years of entry and their educational backgrounds. Not so, I was told. The membership application forms which contain this information are not retained; the membership roster, maintained by the Press and based exclusively on dues payments, contains only names and addresses. Bent, but not bowed, I perceived an opportunity to make at least one solid contribution to the Society for conferring on me its mantle of leadership, and strove, with the invaluable assistance of Judy Brown and Hope Punnett, to obtain some relevant data. Our sources of information were three: the archives of our Society; the minutes of the annual meetings; and the recent poll of the active membership. Here is what we've learned. Our Society currently has about 1,720 members; of these about 43% are PhD's, about 40% are MD's, or DDS's, about 14% are MS's or MA's, and the remainder are BA's, BS's, RN's, and JD's. As seen from figure 1, which plots total membership against year, our Society has grown considerably since it was founded in 1948. This growth was initially uneven—a spurt in the early 1950s, and a lag in the latter half of that decade. In the ensuing 20 years, however, our numerical growth has been reasonably linear with time.

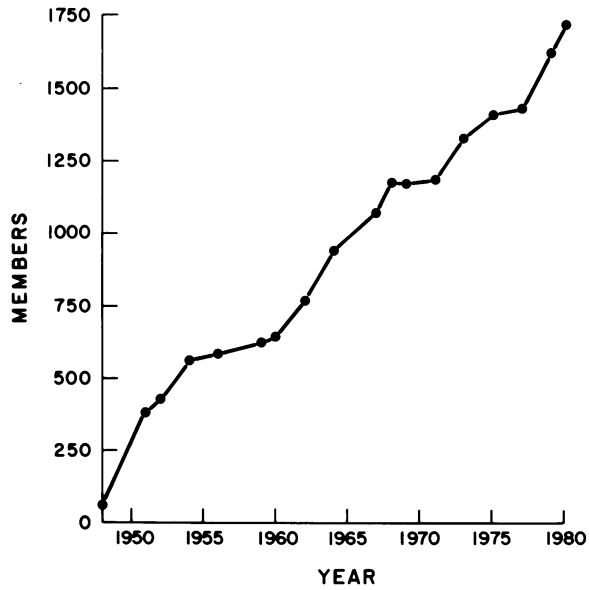

FIG. 1.—Membership in the American Society of Human Genetics (1948–1980)

I have also attempted to chart the relative growth of each of the Society's largest components, that is, PhD's, MD's plus DDS's, and MS's plus MA's. These results, shown in figure 2, are subject to at least two kinds of bias: that conferred by incomplete returns (since only 55% of you responded to the recent poll of the membership); and that conferred by the fact that we were able to poll only living, active members. These biases affect both the numbers on the ordinate and the hyperbolic nature of the upper two curves. Nonetheless, several observations can be made. First, the Society has had and continues to have relatively equal numbers of MD's and PhD's, and these two groups constitute the preponderant ones in the organization. Second, master's degree recipients, largely, of course, as a result of the creation of the several genetics associates programs, have swelled our numbers only during the past decade. Finally, and significantly, in none of the years of the 1970s have the new members of the Society with master's degrees equaled either the new members with MD backgrounds or those with PhD training. To me, there is nothing about these numbers which suggests that the welcome presence of genetics associates in our midst is likely to affect in any dramatic or unwelcome way the nature of our Society's human mixture.

Having satisfied myself that the Society continues to grow and differentiate, I was next curious to learn something about our functional status. Since, from its inception, ours has been fundamentally a scientific organization, it is its scientific activity which I have probed. This I have done by reviewing the number and subject matter of the abstracts submitted by our membership to the annual meeting over the 20-year interval that such a mechanism has been used to construct the annual program.

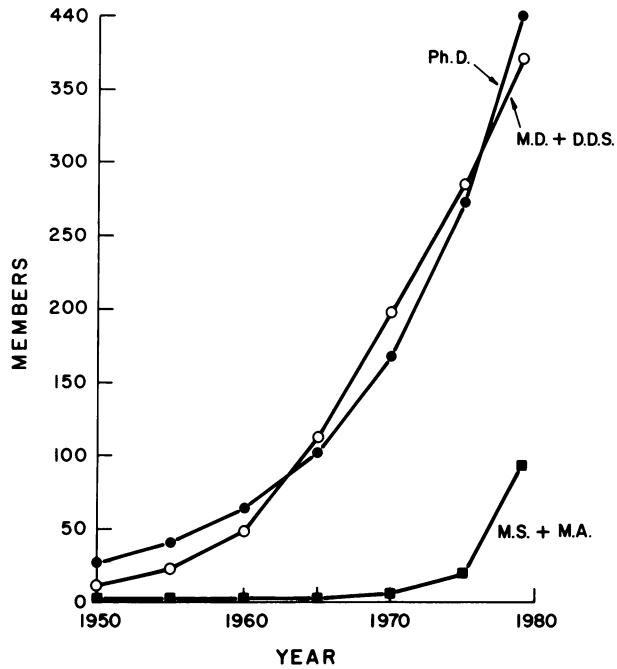

FIG. 2.—Breakdown of membership by educational background. Data obtained from 1980 poll of active members.

With the help of Jim Neel, who provided me with abstract booklets collected prior to 1965 (when the program and abstracts began to appear regularly in the *Journal*), I have undertaken two kinds of assessment: a simple tabulation of the total number of abstracts submitted; and a not-so-simple breakdown of the abstracts into two broad subject categories—"clinical" and "nonclinical." Needless to say, the latter task required prior definition of the vague word "clinical." I classified as clinical any abstract concerned with the etiology, pathogenesis, pathophysiology, description, diagnosis, treatment, or prevention of a known genetic disease. Given this broad but, I would hold, legitimate definition, and encouraged that "spot checks" by a few other junior and senior colleagues did not give distinctly different results, I obtained the data shown in figure 3. Note, first, that the total number of abstracts submitted to our annual meeting has been increasing throughout the 20-year interval examined, this increase being almost linear during the past decade. Note, too, that this recent increase is reflected largely, though not exclusively, by a similarly linear increase in submission of abstracts dealing with clinical subjects.

These data are presented in a slightly different way in figure 4. Here, those abstracts deemed "clinical," expressed as a fraction of total abstracts submitted, are plotted along with the fraction of our membership considered a priori most likely to have carried out clinical investigation, that is the MD's and the DDS's. Note that the marked increase in submission of clinical abstracts during the 1970s has occurred during an interval in which there has actually been a modest fall in that

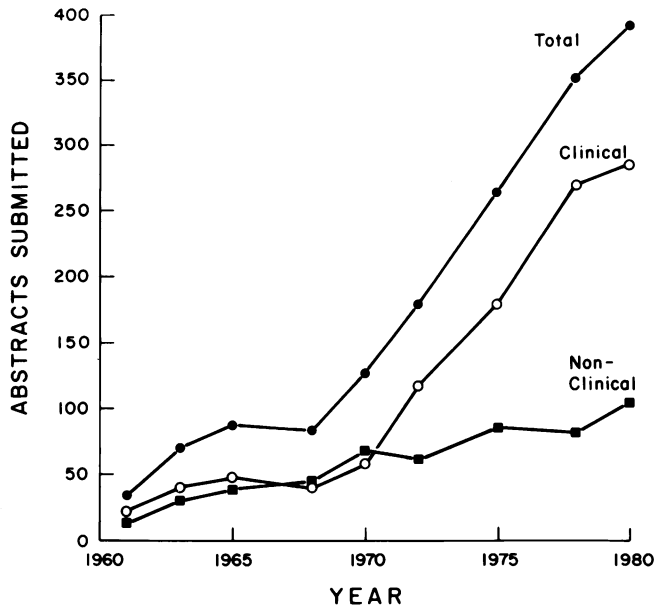

FIG. 3.—Abstracts submitted to the Annual Meeting of the American Society of Human Genetics (1961–1980).

portion of our Society's membership having MD or DDS training. Surely these data refute the charge that we need a new society for clinical geneticists. Rather they suggest that our Society, while maintaining a strong commitment to fundamental research, is responding to the exhortations from NIH and elsewhere that our health-related research be concerned increasingly with applications to sick people or those at risk.

From these and other data, I conclude that our Society meets four critical criteria of a healthy scientific organization: a growing membership; an expanding scientific forum; a respected journal; and a solvent treasury. Proper attention to these matters is essential if we are to continue to be successful in meeting the first two objectives framed by the founders of our Society: ". . . to bring into closer contact investigators in the many general fields of research which involve human genetics" and "to encourage and integrate research in human genetics." But our founders added a third objective, namely, "to deal with other problems related to human genetics," and it is to this wisely vague purpose that I now turn. I do not know what "other problems" such men as Strandskov, Cotterman, Muller, and Snyder had in mind in the late 1940s when they wrote our Constitution, but I doubt that even these farsighted individuals had the clairvoyance to appreciate that, in slightly more than one generation, our field would face "other problems" with such names as board certification, genetic screening in the work place, recombinant DNA, and Love Canal. Each of these problems has arisen because of scientific progress. Just as the rapid evolution of the discipline of clinical genetics declared the need for the American Board of Medical Genetics, so did advances in biochemical genetics lead

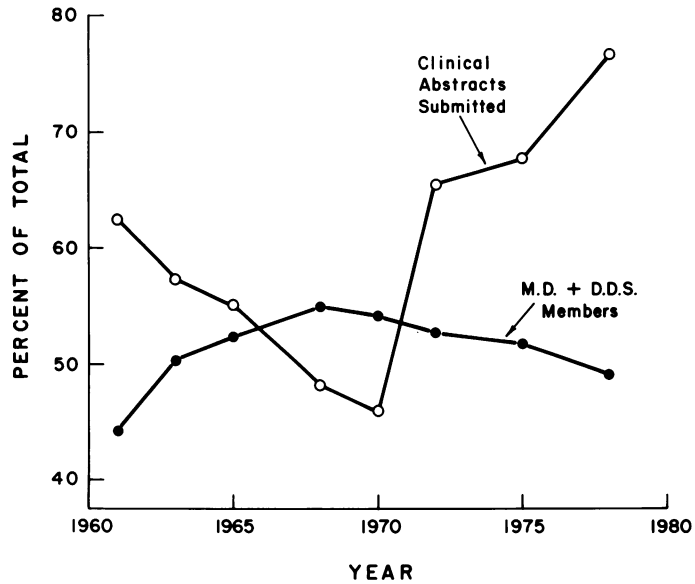

FIG. 4.—Relationship between clinical scholarship and clinical training in the American Society of Human Genetics (1961–1980). See text for additional details.

to population screening for certain deleterious or potentially deleterious traits. Just as the remarkable discoveries in molecular biology resulted in the ability to make recombinant DNA, so did new knowledge about the structure and appearance of the human chromosome lead to the cytogenetic studies carried out on residents at Love Canal. In contrast to this commonality of origin, these progress-born problems differ dramatically in scope, in complexity, and in the strategies needed for solution. Board certification in medical genetics, for example, was perceived, correctly I believe, as an internal problem of our Society, and we have set in motion a rational mechanism for its solution. That is not to say that the problem will yield quickly or that mistakes will not be made, but rather that the problem has been defined and the struggle to resolve it has been joined. The other three problems which I mentioned differ fundamentally from that concerned with board certification because, rather than being identified in the relatively cloistered setting of our Society, they were either born in or almost immediately thrust into the public arena. And that, I offer, is what makes them so difficult for our professional Society.

Let us take the Love Canal controversy as an example. If the Environmental Protection Agency had asked the American Society of Human Genetics for advice concerning the proper way to determine whether citizens at Love Canal had an increased frequency of chromosome breaks, I am certain that our Genetics Services Committee, or our Social Issues Committee, or a select ad hoc committee expressly established for this important purpose would have indicated the need for proper controls, for informed consent, for detailed statistical evaluation of the data, for long-term follow-up, and for caution in assigning clinical significance to the chromosome breaks if, in fact, a statistically significant increase in them was found. But

such advice was not sought from the officers of this Society—not at the outset, not after the Picciano report was presented, not after each of the two subsequent review committees was convened, not to this day. Why? some of you may ask. Surely, governmental agencies realize that our Society, the largest and broadest one in the field of human genetics, contains the basic laboratory scientists, clinicians, and epidemiologists needed to give expert counsel on such a matter. That realization I am sorry to say, is not widespread. Our organization is anything but a household word. In some ways, on some days, I, and I'm sure many of you, might prefer it that way—might prefer that our Society limit its functions to the traditional annual meeting and the *Journal*, and stay out of such messes as the Love Canal controversy with its bent toward litigation at least as much as toward information. But it is too late for that ostrichlike stance. For more than a decade we've had committees named Social Issues, Genetic Services, and Public Information and Education because our members and leaders understood that scientific progress was swiftly making our field visible to and vulnerable to the public. I have watched these committees operate during my years on the Board of Directors and in my current capacity. They try very hard to identify issues, inform our members, and advise appropriate groups, but their tasks are made terribly difficult by the basic features of our organization: a president whose one-year term expires before he or she even knows what issues the committees are examining; a Board of Directors that traditionally meets once a year coincident with the hustle and bustle of our annual meeting; and a pattern of governance which denies our committees a regular budget, and makes it necessary for the full Board to endorse virtually any statement the committees make. Some of these structural problems are solvable by such modest adjustments as better use of the president-elect, additional meetings of the Board, and well-justified budgets for certain committees. More difficult is the question about prior endorsement of committee actions by the Board and/or the president, but increased use of conference calls and the Xerox machine could help significantly. I am convinced, however, that, whereas oiling the creaky machinery of our Society will help us respond somewhat more efficiently to those public issues presented to us, such measures will not have any appreciable effect on the more fundamental problem—namely, that of increasing the likelihood that our opinion will be sought about those matters in the domain of our knowledge and experience. Toward a solution to this problem I have three recommendations. First, I believe the Society should join the Council of Academic Societies of the Association of American Medical Colleges. The AAMC is among the most potent political forces in Washington representing the biomedical academic sector, and its Council contains representatives of 63 academic societies like ours. In fact, scrutiny of its membership reveals that ours is among only a few large, national groups not represented. Second, I think we should join the Coalition for Health Fundings, a group of nearly 60 nonprofit organizations which have joined together "to increase their impact on the federal appropriations process for health programs." Membership in these organizations will put our Society in the same position as that of other groups, namely, that of hearing about public matters, and as importantly, being asked for our response in areas of our concern and expertise. Such affiliations will, at least,

allow us to inform our membership, and, at most, permit us to make a real contribution before the fact rather than wringing our hands after it. And, third, I think the time has come to establish a permanent executive office for the Society, preferably in Washington. This office would give us another ear and, when appropriate, another voice. It would, as importantly, reduce the overwhelming burden on our secretarial office, and permit the University of Chicago Press to get on with its rightful business of publishing our excellent journal, and get out of the anachronistic business of acting as our executive office. If each of these recommendations is followed, it will cost money, but our fiscal position is sound and our dues are so low that a modest increase would not be too painful. I realize that these proposals will, if enacted, change modestly the way our Society operates, but I am convinced that our "one-horse shay" must be retired.

Let me conclude by shifting the focus of my remarks from our particular academic Society to academic life in general. Biomedical scientists (particularly MD's), department chairmen, deans, society presidents, and other self-appointed pundits have discovered a new song in recent years. It is called the "biomedical wail," and it goes something like this: Why is federal funding for biomedical research leveling off? Why doesn't the public thank us for all our marvelous work? Why aren't today's medical students stampeding to follow in our academic footsteps? Why must we work so hard and get paid so little? Why must we spend so much time preparing grants and writing progress reports? This "hit" song is played so often that you would think we were mimicking the Rolling Stones' blockbuster whose sad refrain is: "I can't get no satisfaction." I have a few thoughts about this song for the young and not-so-young alike.

To my eager, ebullient, energetic young colleagues I say, don't believe a word of it. The complaints you hear are either the self-conscious responses of people who feel guilty about having such a good time, or the outward manifestations of our general preoccupation with disaster and decline, or the unmuted hyperbole which characterizes modern expression. If you get tired of having your shoulder cried upon, ask the weeper about such academic perquisites as travel, freedom, and challenge. Just remember, nobody forced all these middle-aged academics to choose the careers they have selected. More importantly, remember that the field of human genetics promises to be as exciting (or more so) in the 1980s and 1990s as it has been in the 1960s and 1970s, and it would be a shame for any of you to miss the fun.

To my weary, wary, and worried not-so-young comrades I say, be fair. When your experiments don't work, or your grant deadline is approaching, or your patients appear ungrateful, don't unburden yourself to your undergraduates, your graduate students, or your postdoctoral fellows. Lock yourself in the closet, jog, complain to your spouse, have a beer, but don't frighten the kids. They might just take you seriously. If you must tell it like it is, please be sure to give equal time to the privileges and pleasures of academic life, to the dazzling sense of well-being that follows scientific discovery, and to the excitement that each of us knows lies beyond our current horizons.

I wish each of you a good meeting, a good year, and a good decade.